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UNITED STATES DISTRICT COURT
NORTHERN DISTRICT OF CALIFORNIA
SAN FRANCISCO

CALIFORNIA TRIBAL FAMILIES COALITION,
YUROK TRIBE, CHEROKEE NATION, FACING
FOSTER CARE IN ALASKA, ARK OF FREEDOM
ALLIANCE, RUTH ELLIS CENTER, and TRUE
COLORS, INC.,

Plaintiffs,

vs.

ALEX AZAR, in his official capacity as Secretary of
Health and Human Services, LYNN A. JOHNSON,
in her official capacity as Assistant Secretary for the
Administration for Children and Families, U.S.
DEPARTMENT OF HEALTH AND HUMAN
SERVICES, and ADMINISTRATION FOR
CHILDREN AND FAMILIES,

Defendants.

Case No. 3:20-cv-06018

BRIEF FOR *AMICUS CURIAE*
AMERICAN ACADEMY OF
PEDIATRICS IN SUPPORT OF
PLAINTIFFS' MOTION FOR
SUMMARY JUDGMENT

INTEREST OF AMICUS CURAE

Amicus is the American Academy of Pediatrics (AAP), the largest professional association of pediatricians in the world. Amicus represents 67,000 primary care pediatricians, pediatric medical subspecialists, and surgical specialists who are committed to the attainment of optimal physical, mental, and social health and well-being for all infants, children, adolescents, and young adults. In its dedication to the health of all children, Amicus strives to improve health care access and eliminate disparities for children and youth involved in the child welfare system. Amicus works to ensure that public policies support the thriving of all children and youth and their families, including American Indian and Alaska Native (“AI/AN”), lesbian, gay, bisexual, transgender, and questioning (“LGBTQ”) children, and “two-Spirit” AI/AN youth, a unifying term that encompasses both gender identity and traditional Indigenous understandings of identity and which is a widely used term in Indigenous communities across North America.

AAP regularly publishes peer reviewed studies about pediatric health, including about the health of children in foster care. AAP also engages in pediatrician advocacy on these issues. AAP chapters and districts also engage in regional, state, and local efforts to address the physical, mental, social, and emotional health needs of adolescents and young adults in foster care.¹

Beginning in 2008, Amicus has commented on the Adoption and Foster Care Analysis and Reporting System (“AFCARS”) legislation, including most recently in 2019 when Amicus voiced its strong opposition to the revisions proposed by the Notice of Proposed Rulemaking to amend AFCARS, which were finalized in the 2020 AFCARS regulations.²

SUMMARY OF ARGUMENT

Amicus submits this brief to inform the Court of the predictable obstacles that will impact the health and well-being of LGBTQ and AI/AN foster care youth if collection of critical AFCARS data related to AI/AN and LGBTQ youth in out-of-home care is not reinstated.

¹ See AAP Policy Statements, clinical reports, and technical reports, accessible at <https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/healthy-foster-care-america/Pages/Policy-Statements.aspx>.

² See AAP Comment Letters dated March 5, 2008; October 21, 2010; April 10, 2015; August 28, 2017; June 13, 2018; June 13, 2019.

Based on its peer reviewed publications and the experience of its chapters and members, Amicus is aware that (i) collection of data is critical to promoting healthy children, particularly those in foster care that face unique and disparate health challenges; (ii) LGBTQ and AI/AN children also face unique vulnerabilities and health challenges; and (iii) inadequate or incomplete data is likely to adversely impact health care for LGBTQ and AN/AI children in foster care.

As Amicus stated in its 2019 letter submitted in opposition to the delay of the 2016 final AFCARS rule: “These proposed revisions to the 2016 final rule would be a significant obstacle in the advancement of children’s health for those within the foster care system, and we strongly oppose them.” Quality child welfare data collection is crucial to the improvement of children’s health and wellbeing. The health needs of LGBTQ and AI/AN youth will not be adequately addressed without data regarding their unique health issues. The changes made to the 2016 final AFCARS rule will impede the advancement of children’s health for those within the foster care system, and particularly for LGBTQ and AI/AN youth. For this reason, the Court should reverse the changes to streamline the 2016 AFCARS rule and reinstate data collection on AI/AN and LGBTQ youth in foster care.

ARGUMENT

I. Collection of data is critical to promoting healthy children, and AFCARS offers states a critical tool for understanding children’s health and well-being.

Safety, permanency, and the wellbeing of children in foster care are three key precepts that inform the work of the Administration for Children and Families (“ACF”), state child welfare agencies, and professionals serving children in foster care, including pediatricians.³ A thorough understanding of a child’s health status is essential in advancing those three precepts. Wellbeing remains the most complex to define, measure, and improve.

Quality child welfare data collection is imperative to the improvement of children’s health and wellbeing. As state and local child welfare agencies look to improve the overall health of the children in their care, effective and robust data collection tools are increasingly necessary to target

³ See AAP Comment Letter dated June 13, 2019 (<https://www.regulations.gov/comment/ACF-2018-0003-0260>).

1 public health interventions to ensure optimal population health outcomes. AFCARS offers states a
 2 critical tool for understanding children's health and wellbeing and provides ACF with essential
 3 information for enforcing federal child welfare laws. By collecting information related to child
 4 health and identifying trends, AFCARS allows state agencies and the federal government to better
 5 promote the health and wellbeing of children in the foster care system and make changes where
 6 necessary to better respond to the needs of this population. This can provide long-term benefits to
 7 the youth and save costs in the long term.

8 AFCARS plays a key role in tracking the experience of children in foster care and the
 9 success of implementation of federal child welfare law at the state level. With increasing numbers
 10 of children entering foster care due to issues such as poverty, the ongoing opioid epidemic, and the
 11 COVID-19 pandemic, it is critical that states and ACF collect useful data that support improved
 12 access to care for vulnerable children. High-quality data is particularly essential to identifying and
 13 responding to changing circumstances resulting from the COVID-19 pandemic and its impact on
 14 the child welfare system and the families it serves.

15 The health-related elements within the 2016 AFCARS final rule lend themselves to the
 16 improved coordination of the health and social services necessary to support the safety,
 17 permanency, and wellbeing of children in out-of-home care. Ongoing trends in child welfare data
 18 improvement, including ACF's work to transition the Statewide Automated Child Welfare
 19 Information System to the Comprehensive Child Welfare Information System, underscore the
 20 importance of ensuring the collection of child welfare and health data to improve child outcomes.
 21 These ongoing trends point to the critical importance of collecting quality data through AFCARS
 22 to support improved child health and wellbeing.

23 **II. Children, adolescents, and young adults involved in the child welfare system often**
 24 **have complex health care needs.**

25 Children in foster care frequently move through multiple placements, fragmenting their
 26 medical care, and placing children at risk for having medical, developmental, and psychiatric
 27 needs that remain either unaddressed, untreated, or incorrectly treated, and results in the
 28 misidentification of needs, such as inaccurate diagnosis of mental health conditions due to a lack

1 of complete trauma history. In the absence of mitigating intervention, adverse childhood
 2 experiences can have detrimental health implications across the life span. A child's experience of
 3 removal from their family of origin to foster care is by itself a traumatic experience, even when
 4 necessary for the child's health and safety. This coupled with earlier trauma that led to the
 5 removal may contribute to failure to thrive, developmental delays, and behavioral health
 6 challenges. The effects of toxic stress in early childhood on the neuroendocrine-immune system
 7 not only leads to psychological and psychiatric morbidity but also can result in higher risks for
 8 later medical morbidity.⁴

9 As a result, physician and nonphysician clinicians often face significant barriers in
 10 providing appropriate health care services to children in foster care. Key challenges pediatricians
 11 may encounter while providing care for a child in foster care are often due to incomplete or
 12 unavailable health information, including: information about immunizations; newborn health
 13 screening results; prescribed medications, including psychotropic medications; allergies; chronic
 14 illnesses; hospitalizations; surgeries; vision or hearing loss; family history; dental history;
 15 psychosocial history, including childhood and caregiver trauma history; and developmental or
 16 educational problems. The child is frequently accompanied by a myriad of individuals
 17 (caseworkers, transporters, and new foster parents) who may have little to no knowledge of the
 18 child's current medical or social situation. These factors combined with fragmentation of care and
 19 medical consent laws that vary by jurisdiction can create difficulty identifying who has the
 20 authority to consent for health care on behalf of the child. Inadequate resources for evaluation and
 21 treatment limitation is caused by a combination of workforce, systems, and funding issues.⁵

22 Many of the children entering foster care have been exposed to significant levels of trauma
 23 and multiple adverse childhood experiences. Reports have shown numbers as high as 25% of
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25 ⁴ "Pediatrician Guidance in Supporting Families of Children who are Adopted, Fostered, or in
 Kinship Care" (<https://pediatrics.aappublications.org/content/146/6/e2020034629>).

26 ⁵ AAP Policy Statement "Health Care Issues for Children and Adolescents in Foster Care and
 Kinship Care" by the Council on Foster Care, Adoption, and Kinship Care, Committee on
 27 Adolescence, and Council on Early Childhood
 28 (<https://pediatrics.aappublications.org/content/pediatrics/136/4/e1131.full.pdf>)

1 youth in foster care receiving clinical diagnoses of Post-Traumatic Stress Disorder.⁶ Evidence
 2 shows that addressing childhood trauma sooner improves children’s lifelong health and wellbeing
 3 and can reduce future health care costs associated with long-term sequelae of trauma.⁷ Access to
 4 accurate data, by recording in detail the health conditions of children in foster care, allow health
 5 care providers to better assess their health status. This will allow for a better analysis of the
 6 improvements necessary for in-service delivery to meet the needs of this population.

7 Several decades of research has firmly established that the health care needs of children in
 8 out-of-home care far exceed those of other similarly situated children living in poverty. Despite
 9 the overwhelming evidence of need, studies consistently demonstrate that many health care needs
 10 for children in the foster care system go unmet. “Children in custody have worse health status
 11 compared with the general population in part because of poor information sharing between the
 12 health care system and the child protection system.”⁸

13 “Children in protective custody have more medical, behavioral, and developmental
 14 problems that require health care services than the general population. These health problems are
 15 compounded by poor information exchange impeding care coordination. Health care providers
 16 often do not know which of their patients are in protective custody and are not privy to the critical
 17 social history collected by child protective services, including placement history and maltreatment
 18 history. Meanwhile, the custodial child protection agency and designated caregivers (i.e., foster
 19 caregivers and kinship providers) often lack vital elements of the history of the children in their
 20 care, which can result in poor health care delivery such as medication lapses, immunization delay,
 21 and poor chronic disease management.”⁹

22 Medical treatment targeted at the unique and disparate needs of foster children requires
 23 data for preclinical and clinical treatment efforts. For example, Amicus has published guides for
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25 ⁶ https://www.aap.org/en-us/Documents/hfca_foster_trauma_guide.pdf.

26 ⁷ See AAP Comment Letter dated June 13, 2018 (<https://www.regulations.gov/comment/ACF-2018-0003-0151>).

27 ⁸ “Improving Information Sharing for Youth in Foster Care” by Mary V. Greiner, Sarah J. Beal,
 Judith W. Dexheimer, Parth Divekar, Vikash Patel and Eric S. Hall.
 (<https://pediatrics.aappublications.org/content/144/2/e20190580>).

28 ⁹ *Id.*

1 pediatricians in identifying and treating toxic stress in children who have been adopted or fostered.
 2 These guides describe the challenges for developing treatments for foster children and how data is
 3 crucial to avoiding interventions that are ineffective or even detrimental:

4 Children with a history of toxic stress may present to the pediatrician with sleep problems,
 5 toileting problems, anger, aggressive behaviors, depression, or difficulties sustaining
 6 attention. Knowledge of the relationship between these behavior problems and earlier
 7 stressful life experiences is important in guiding effective treatment; failure to understand
 8 this relationship may result in treatment approaches that are inefficient, ineffective, or even
 9 counterproductive. Identifying the role of toxic stress in these symptoms early will allow the
 10 pediatrician to mobilize available community resources and mitigate deleterious effects on
 11 the child's subsequent socialization and development.¹⁰

12 In summary, lack of data is itself a frequent challenge to providing healthcare to children in foster
 13 care, thereby exacerbating traumatic circumstances that give rise to health challenges that are
 14 different than those faced by other populations.

15 **III. LGBTQ and AI/AN children face additional unique vulnerabilities and health** 16 **challenges.**

17 LGBTQ youth who come to the attention of the child welfare system face additional
 18 trauma and have unique vulnerabilities and needs beyond those of other children in foster care.
 19 Significant health disparities exist for sexual minority youth related to depression and suicidality,
 20 substance abuse, social anxiety, altered body image, and other mental health issues. Sexual
 21 minority youth suffer higher rates of depression¹¹ and have more than twice the rate of suicidal
 22 ideation compared to the average of all other children in the same age range. "[LGBTQ] youth are
 23

24 ¹⁰ American Academy of Pediatrics and Dave Thomas Foundation for Adoption. Helping Foster
 25 and Adoptive Families Cope with Trauma: A Guide for Pediatricians. Elk Grove Village, IL:
 26 American Academy of Pediatrics; 2013. Available at: www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/healthy-foster-care-america/Documents/Guide.pdf.

27 ¹¹ AAP Policy Statement "Office-Based Care for Lesbian, Gay, Bisexual, Transgender, and
 28 Questioning Youth" by AAP's Committee on Adolescence (July 2013)
<https://pediatrics.aappublications.org/content/132/1/198>.

1 overrepresented in foster care and unstable housing and report worse school functioning, higher
 2 substance use, and poorer mental health compared with heterosexual youth in stable housing.
 3 Affirmative care is needed.”¹²

4 Despite some advances in public awareness and legal protections, youth who identify as
 5 LGBTQ continue to face disparities that stem from multiple sources, including inequitable laws
 6 and policies, societal discrimination, and a lack of access to quality health care, including mental
 7 health care. Such challenges are often more intense for youth who do not conform to social
 8 expectations and norms regarding gender.¹³

9 AI/AN populations have substantial health inequities, and most of their disease entities
 10 begin in childhood. In addition, AI/AN children and adolescents have excessive disease rates
 11 compared to the general pediatric population. Not only do AI/AN youth face medical access
 12 barriers, but they also have a higher prevalence of chronic stress and adverse childhood
 13 experiences and exposure to environmental hazards resulting in poorer health outcomes when
 14 compared with the general population.¹⁴ AI/AN youth in foster care are more likely to have
 15 special health care needs compared with others in foster care.¹⁵

16 The challenges faced by LGBTQ and AI/AN youth merge for two-Spirit AI/AN youth as
 17 two-Spirit youth are significantly at risk for negative health disparities. In the 2015 US National
 18 Transgender Health Survey, transgender AI/AN respondents reported having experienced
 19 harassment (86%), physical assault (51%), and sexual assault (21%). Fifty-seven percent of
 20

21 ¹² “LGBTQ Youth in Unstable Housing and Foster Care” by Laura Baams, Bianca D.M. Wilson
 22 and Stephen T. Russell (<https://pediatrics.aappublications.org/content/143/3/e20174211>).

23 ¹³ AAP Policy Statement “Ensuring Comprehensive Care and Support for Transgender and
 24 Gender-Diverse Children and Adolescents” by Committee on Psychosocial Aspects of Child and
 25 Family Health, Committee on Adolescence and Section on Lesbian, Gay, Bisexual, and
 26 Transgender Health and Wellness (October 2018)
 27 (<https://pediatrics.aappublications.org/content/142/4/e20182162>).

28 ¹⁴ Bell S, Deen JF, Fuentes M, et al, AAP COMMITTEE ON NATIVE AMERICAN CHILD
 HEALTH. Caring for American Indian and Alaska Native Children and Adolescents. *Pediatrics*.
 2021;147(4):E2021050498
 (<https://pediatrics.aappublications.org/content/pediatrics/147/4/e2021050498.full.pdf>).

¹⁵ *Id.*

1 AI/AN youth identifying as transgender have attempted or contemplated suicide, compared with
 2 4.6% of the general US population and 33.7% of transgender youth as a whole. In this same
 3 study, 23% of transgender respondents (all ages) identifying as AI/AN experienced unemployment
 4 in the last year. In another study, youth at the intersection of gender and racial identity had higher
 5 rates of risk behaviors and emotional distress.

6 Collecting data within AFCARS related to the Indian Child Welfare Act (“ICWA”) is
 7 necessary for ensuring the law’s effective implementation and the related child health benefits it
 8 offers to AI/AN youth.¹⁶ ICWA is a critical federal child welfare law, promoting maintenance of
 9 familial and cultural ties to promote children’s health, safety, permanency, and wellbeing.
 10 Appropriate ICWA implementation is important for minimizing child trauma and promoting
 11 optimal parent-child attachment and facilitation of maintained connection to extended family and
 12 culture which serve as protective factors against mental and emotional disorders. Amicus strongly
 13 opposes the removal of the data elements related to ICWA and urges the inclusion of all ICWA
 14 elements from the 2016 AFCARS rule which were removed as a result of the 2020 final AFCARS
 15 rule.

16 **IV. Inadequate or incomplete data is likely to adversely impact health care for LGBTQ**
 17 **and AI/AN children in foster care.**

18 It is widely understood and accepted that data is both necessary and desirable to identify
 19 health challenges for any population. As discussed above, peer-reviewed research demonstrates
 20 that children in protective custody have more medical, behavioral, and developmental problems
 21 that require health care services than the general population, and “[w]ithout information sharing,
 22 efficient and high-quality care cannot be provided to this vulnerable population, and the
 23 effectiveness of current programs cannot be measured.”¹⁷ Measuring the incidence of health
 24 issues is imperative to understand the scope of specific health challenges so that appropriate
 25

26 ¹⁶ AAP works extensively to promote the health of Native children and to support policies that
 27 ensure their access to needed health services and address the unique disparities they face.

28 ¹⁷ “Improving Information Sharing for Youth in Foster Care” by Mary V. Greiner, Sarah J. Beal,
 Judith W. Dexheimer, Parth Divekar, Vikash Patel and Eric S. Hall
 (<https://pediatrics.aappublications.org/content/144/2/e20190580>).

resources can be allocated and so that preventative care can be attempted rather than relying exclusively on treatment which can be more expensive and less effective.

As discussed above, LGBTQ and AI/AN populations have unique vulnerabilities, and identifying these health challenges requires data, instead of relying only on anecdotal stories or impressions of patients or caregivers. These unique vulnerabilities mean that data is necessary to ensure that the distinct needs of LGBTQ and AI/AN are allocated appropriate resources and so that preventative efforts can be developed and applied.

Without data regarding LGBTQ and AI/AN needs, tracking is not possible, and the U.S. Health and Human Services' Administration for Children and Families will not have requisite data to inform their efforts to address the unique and significant health needs of this vulnerable population. Collecting and analyzing data to measure and verify the effectiveness of services helps organizations make informed policy and practice decisions toward improving outcomes for children and families. If the data is unreliable or not useful, the system could hamper rather than facilitate efforts to improve children's lives. "One of the biggest benefits of gathering and maintaining accurate data systems is using data as a marker of progress. Without accurate, up-to-date data, it is difficult for policymakers to make informed decisions about policies that aim to serve children and families...Lacking an accurate baseline of data, it is difficult to discern whether youth's outcomes are improving or declining as a result of policy and practice changes. In short, it's virtually impossible to measure change without accurate data."¹⁸

Because LGBTQ and AI/AN populations in foster care have additional unique concerns, data about those unique concerns is necessary to develop treatments targeted at these children. In many cases, data will be even more important to developing treatments than data is for treatment for other populations given the disparities facing these youth.

CONCLUSION

For the foregoing reasons, the Court should grant the Plaintiffs' motion for summary judgment.

¹⁸ https://childandfamilypolicy.duke.edu/wp-content/uploads/2015/09/CWELC_Report_2015.pdf.

1 Respectfully submitted,

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3 Dated: May 27, 2021

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